

Brook Lodge Conference Focuses On Future Of High-Tech Ventilator-Dependent Children

by Eugene E. Bilotti, MSW

In October, 35 people who work daily, hourly and weekly with ventilator-dependent patients came together for a conference in Augusta, MI. Some of the people there had committed major portions of their lives to this population. We didn't have rigid agenda or time frames — we had groups in which we talked about ventilator-dependent children — how to get them home, their problems, what our experiences have been, what we should look forward to in the future. Consequently, we wanted to bring these people together and share experiences for three main reasons.

One is best summarized by the last few words that Betty Wartenberg spoke at the Surgeon General's Workshop in Washington. It made the hair on my neck stand up in the back, and I shivered. Betty, when she finished her speech, said, "I thank you for not pulling the plug on Donnie."

The second experience occurred at the end of the seminar when the very imposing figure of the Surgeon General of the United States stood before us and took the gavel and hit it hard and said, "I'm supposed to make decisions. I declare that this conference is a success, and we're adjourned." And we left.

Those two moments come together to make our first point: We cannot give up on these children, and we shall not give up on these

children. We shall do what we can to maximize their potential, and to make them all what they are capable of being — socially, educationally, and physically.

Our second point is this: These children were not intended to live in an intensive care unit or a high-risk nursery. High-risk nurseries have other reasons for being. These children need a better home. They need better alternative living solutions — if not their own home, then a home-like setting or something else.

Third, one of the major issues we face after medical stability is, "How are we going to pay for these children to go home?" We've heard the figures, and they are hard to believe. Do you really believe that we saved the state of Illinois \$5 million in the last four years on these children? These figures are overwhelming.

The first time I was interviewed for a local paper, they asked how much the children's care cost. I said some of these children's care costs \$45,000 a month. They put down \$45,000 a year. I went back to them and said, it's \$45,000 a month, not a year — a month. They said that's not possible.

It's not only possible, it's happening.

Therefore, we addressed funding issues at Brook Lodge. You would be interested to know that we have no iron-clad solutions.

However, one may be through Title XIX of the Medicaid waiver which is not targeted to ventilator-dependent children alone, but for all severely disabled children who can best be served in their own home.

When we approach an insurance company and show them cost savings and approach them as colleagues, they are willing to listen and will sometimes revise their policies in order to cover these children.

Third, other than the Crippled Children's programs, Title XIX, and the Maternal Child Health Block Grant, there are really no other sources of funding, with the exception of grants and gifts. In Illinois and other states, we can save approximately \$22,000 a month by creating a little ambulatory intensive care unit in the home. It looks like a home, but yet it has equipment — a ventilator, a suction machine, and sometimes a backup generator or ventilator.

We did not spend all of our time on funding at that conference. We also discussed the role of parents. The parents are critical — they are really the case managers — they run the show and make the operation occur. We also talked about involving the parents in training.

Another item we emphasized was the differences that occur from family to family, child to child, situation to situation. They're all different. We had to go to our tenth

child before we had a duplicate diagnosis. Consequently, we have no prototype and no average child. We can't really describe a ventilator-dependent child; therefore, we have to have exhaustive detailed care plans for these kids in the home. How detailed? I recently saw one that ran almost 400 pages. Children's Home Health Network is committed to considering every contingency when the child goes home. You have to keep the roads open, make sure the lights are on and then, while saying that, we have to keep saying to ourselves that every child is a home discharge candidate. Sometimes we have to come to the bitter grips of saying, "This child is not a candidate for home discharge," and that hurts us very much.

We are a government that is ruled by regulations, therefore we are developing standards, guidelines, and regulations for getting these children home.

Home care is not always enough — we need other alternative kinds of places for these children to live such as medical foster homes. Although it may sound impossible,

the Department of Children and Family Services put an ad in the paper concerning a disabled child, and they had 24 people respond. Half of the respondents were nurses, and two or three of them were respiratory therapists. Out of that group we turned out a very, very fine candidate for a medical foster home. We are in the process now of drawing up some guidelines and directions for medical foster homes. There are people who would like to take these children into their homes. Sometimes it's not appropriate and sometimes they cannot leave. Therefore, we have to think about other forms — like hospital schools, upgrading of nursing facilities, other pediatric facilities that will gear their way toward this population.

In order to serve this population, you must have very controlled standards and planned guidelines. The whole system that we are talking about is running against the streams of medicine. For years we've said, "Very ill children belong in hospitals." Now we're saying, "Maybe not." Maybe they need to be in the home, and they are going home in large num-

bers. The Brook Lodge Conference devoted part of its time to the language of the future. We looked at what is going to happen to these high-tech ventilator-dependent children in the future. We must not just think of the child alone, but of the family, the community and of all the institutions that are involved. One of the speakers, Dr. Kohrman, said that we must bring together people who are working with this kind of population to determine their educational needs. What kind of planning do they have for the future? What kind of regionalization do we need in order to put these children in the least restrictive environment? Can we not say that the goal for this population is to bring them to the place that is best for them to grow and develop?

Many of these things we have done before, so we need to collaborate and find out from one another what is being done. The hours are long, the demands great, and the payoffs sometimes very hard to see and very hard to measure; but pediatric practice is exciting as we think about home care in the future. ●